

## Section 4: Obtaining Profile Data

The next step in preparing the profile is to obtain the data you will use to address the scope of the profile and answer the epidemiologic questions.

As the profile writer, you need to be aware of several considerations concerning the acquisition and use of data to describe the epidemic in a service area. You also need to know what types of data are available and where to obtain them.

This section presents a *general* discussion of those considerations—the types of available data and where to find them—as preparation for Chapter 3, where these issues are applied to the specific core epidemiologic questions.

### General Data Considerations

The following are considerations for reviewing data and data sources that you may use in the epidemiologic profile:

- **Completeness of the data:** How well does the number of reported HIV or AIDS cases reflect the true number of persons who have HIV infection or AIDS and are thus eligible to be reported? For example, how well does the prevalence of AIDS represent the true number of persons living with AIDS in your service area?
- **Representativeness of the data:** How well do the characteristics from a data source correspond to the characteristics of the overall population? For example, data from a hospital-based sample may not represent all HIV-infected persons or all HIV-infected persons in care in the area covered by the survey.
- **Age of the data:** How old are the data that will be used for analysis? For example, a behavioral survey conducted in 1990 might not provide data that are sufficiently up-to-date for current prevention activities.
- **Timeliness of the data:** How long is the reporting delay between the diagnosis of HIV or AIDS and the report to the health department?
- **Limitations of the data source or variable of interest:** Consider the limitations of the data source or variable. For example, AIDS case data are the only HIV-related data that are consistently available on a population-wide basis in all states by sex, race/ethnicity, age, and mode of HIV exposure. However, AIDS case data may not reflect the characteristics of people who were recently infected with HIV.

- **Surrogate, or proxy, markers:** A proxy variable is used as a marker for other variables when what we really want to measure is too difficult to measure directly. For example, some areas may use sexually transmitted disease (STD) data as a proxy when data on sexual behaviors are not available.
- **Validity of the data:** How well does a variable measure what it is intended to measure? For example, how well was information about age transcribed to the case report from the medical record (how accurate are the case report data compared with those in the medical record)?
- **Small numbers:** You may need technical assistance to interpret the data when analyzing small numbers of cases because small absolute changes in the number of cases can produce large relative or proportionate changes in rates that may be misinterpreted by end users. These analyses may also require the use of advanced statistical tests. Rates calculated from numerators smaller than 20 should be denoted in a footnote as unreliable.

## Types and Sources of Data for Epidemiologic Profiles

This section includes a description of commonly available data and their sources. Several of these sources directly report HIV and AIDS cases and clinical conditions of persons with a diagnosis of HIV infection or AIDS. Other sources are used to round out the picture of the HIV/AIDS epidemic in your service area. Other sources also are used if no HIV incidence data are available. See Appendix A for an expanded list of core and supplemental data sources and references.

Type of Data	Description	Where to Obtain
AIDS surveillance	<p>AIDS reporting began in 1981, and AIDS is a reportable condition in all states and territories. The AIDS surveillance system was established to</p> <ul style="list-style-type: none"> <li>• monitor incidence and the demographic profile of AIDS</li> <li>• describe the modes of HIV transmission among persons with AIDS</li> <li>• guide the development and implementation of public health intervention and prevention programs</li> <li>• assist in the evaluation of the efficacy of public health interventions</li> </ul> <p>State and local health departments actively solicit disease reports from health care providers, laboratories, and other sources. Standardized case report forms are used to collect sociodemographic information, mode of exposure, testing history, and clinical information. AIDS surveillance has been determined to be more than 85% complete.</p>	<p>All 50 states, the District of Columbia, and US territories collect AIDS surveillance data. Contact your state or local service area's HIV/AIDS surveillance coordinator.</p>
HIV surveillance	<p>HIV surveillance data include all persons who meet the 1999 case definition for HIV infection and have been reported to a state or local health department. HIV</p>	<p>As of January 2004, 34 states (Alabama, Alaska, Arizona, Arkansas, Colorado, Florida, Georgia, Idaho, Indiana, Iowa,</p>

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	<p>surveillance data</p> <ul style="list-style-type: none"> <li>• provide a minimum estimate of the number of persons with a diagnosis of HIV infection whose test was confidential</li> <li>• identify emerging patterns of transmission</li> <li>• help detect trends in HIV infections among populations of particular interest (e.g., children, adolescents, women) that may not be evident from AIDS surveillance data</li> </ul> <p>HIV surveillance data also provide a basis for establishing and evaluating linkages to the provision of prevention and early intervention services. They can be used to anticipate unmet needs for HIV care. According to state evaluations, HIV infection reporting is estimated to be 80%–90% complete for persons who have tested positive for HIV.</p>	<p>Kansas, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Texas, Utah, Virginia, West Virginia, Wisconsin, Wyoming), American Samoa, Northern Mariana Islands, Puerto Rico, the Virgin Islands, and Guam have implemented HIV case surveillance, using the same confidential system for name-based case reporting for HIV infection and AIDS.</p> <p>Pennsylvania implemented name-based reporting in areas outside the city of Philadelphia. Connecticut implemented mandatory HIV reporting in January 2002. For adults and adolescents 13 years of age and older, reporting is by name or code (if patients or physicians prefer this method). For children &lt; 13 years of age and for persons who are co-infected with tuberculosis, reporting is by name. New Hampshire allows HIV cases to be reported with or without a name. Five states use names to initiate case reports and then convert to a code (Delaware, Maine, Montana, Oregon, Washington), and 10 areas are using a coded identifier rather than patient name to report HIV cases (California, Hawaii, Illinois, Kentucky, Maryland, Massachusetts, Rhode Island, Vermont, and the District of Columbia).</p>
Behavioral surveillance	<p>Data on behaviors that are relevant to HIV prevention, transmission, and medical care are available from a variety of sources, including general population surveys, surveys of populations at risk for HIV, and surveys of persons with HIV or AIDS. Behavioral data include</p> <ul style="list-style-type: none"> <li>• patterns of, or deterrents to, HIV testing</li> </ul>	Refer to Appendix A to locate sources of behavioral data in your service area.

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	<ul style="list-style-type: none"> <li>• substance use and needle sharing</li> <li>• sexual behavior, including unprotected sex</li> <li>• sexual orientation</li> <li>• health-care-seeking behavior</li> <li>• adherence to prescribed antiretroviral therapies</li> </ul> <p><b>Examples:</b> Supplement to HIV/AIDS Surveillance; HIV Testing Survey; Behavioral Risk Factor Surveillance System; Young Men’s Survey; Survey of HIV Disease and Care Project; Monitoring Trends in Prevalence of STDs, TB, and HIV Risk Behaviors Among Men Who Have Sex with Men Project; Gonococcal Isolate Surveillance Project; CDC HIV Behavioral Surveys; Project One; and the Context of HIV Infection Project</p>	
Clinical data	<p>Clinical data refer to information on the condition(s) of persons with HIV or AIDS. Clinical information is collected so as to understand</p> <ul style="list-style-type: none"> <li>• disease status at the time of diagnosis and later progression (e.g., CD4+ cell count, viral load, opportunistic infections)</li> <li>• type of medical care received</li> <li>• prescription of antiretroviral therapy</li> <li>• type of therapy received</li> </ul> <p>Patient surveys collect data on adherence to therapy and health-care-seeking behavior. Depending on the source, clinical data may represent all cases of reported HIV and AIDS or only a fraction. Because clinical data rely on the extent of documentation in a medical record and an ability to locate the record, they may be incomplete.</p> <p><b>Examples:</b> Adult /Adolescent Spectrum of Disease Project, Survey of HIV Disease and Care Project, AIDS Progression Study, HIV Outpatient Study, and other locally available cohort data</p>	Refer to Appendix A to locate sources of clinical data in your service area.
Demographic data	Demographic data are used to describe social characteristics (e.g., gender, stage of life, and race/ethnicity) of persons in the service area.	Available for state and metropolitan areas from the Bureau of the Census. Also, states maintain census centers. Obtain these data from <a href="http://www.census.gov">http://www.census.gov</a> .
Hepatitis B and C surveillance	Data on hepatitis B and C virus (HBV, HCV) infections may represent markers for needle sharing and sexual behaviors, which can be	State health department and CDC staff. The quantity and the quality of surveillance data differ

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	<p>risk factors for HIV transmission. Data on hepatitis B and C are used to</p> <ul style="list-style-type: none"> <li>• predict the likelihood and rate of spread of viral hepatitis and HIV infections in a community</li> <li>• monitor trends</li> <li>• identify needs for HIV prevention and care services</li> </ul> <p>Acute hepatitis B and C (i.e., clinical illness with laboratory confirmation) is reportable in all states; however, because of underreporting and asymptomatic infections, data are likely to be incomplete. More than 40 states have registries for HBV and HCV infection, and most have laboratory reporting laws requiring reporting of positive serologic test results for HBV and HCV infection. Although serologic markers for HBV infection can distinguish between acute and chronic infection, laboratory reports of positive HCV-antibody results cannot differentiate newly acquired infections from chronic or resolved infections, making it difficult to monitor disease trends for HCV. In addition, many registries are relatively new, and their usefulness has not been evaluated.</p>	<p>between states. Refer to CDC's National Notifiable Disease Surveillance System (soon to become the National Electronic Disease Surveillance System) and the CDC Division of Viral Hepatitis.</p> <p><b>Reference:</b> CDC. <i>Guidelines for Viral Hepatitis Surveillance and Case Management</i>. Atlanta: CDC; 2002. Available at: <a href="http://www.cdc.gov/ncidod/diseases/hepatitis/resource/pubs.htm">http://www.cdc.gov/ncidod/diseases/hepatitis/resource/pubs.htm</a>.</p>
Qualitative methods	<p>Qualitative methods are used to obtain data through observations, interviews, discussion groups, focus groups, and analysis of social networks.</p> <p><b>Example:</b> Rapid Assessment Response and Evaluation project</p>	<p>Health department staff and local community researchers often use qualitative methods to conduct research. Planning group members may also be aware of local studies. Additional information can be obtained from the University of Texas–Southwestern (<a href="http://www3.utsouthwestern.edu/preventiontoolbox">http://www3.utsouthwestern.edu/preventiontoolbox</a>).</p>
Ryan White CARE Act data reports	<p>The CARE Act data report (CADR) is a form used to collect information annually from grantees and service providers funded under Titles I, II, III, or IV of the Ryan White CARE Act. The CADR collects general information on provider and program characteristics, including the types of organizations providing services (such as ownership status), sources of revenue, expenditures, and paid and volunteer staff. Additionally, the CADR is used to collect aggregate demographic information from which duplicates have been removed (e.g., gender, race, age, HIV exposure category) on total counts of clients served by each provider as well as health insurance coverage and utilization data</p>	<p>Available in all 50 states and all 51 EMAs. Obtain these data from local Ryan White Title I or Title II grantees.</p>

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	<p>about medical and support services.</p> <p>The CADR is the only source of Ryan White CARE Act data that is available in all states and eligible metropolitan areas (EMAs). It provides demographic information and service utilization data on all Ryan White CARE Act clients. In some areas, Title I or Title II grantees have access to unduplicated data across an entire EMA or state. Because it is a summary report by provider, the CADR cannot be used to generate demographic cross-tabulations.</p>	
Sexually transmitted disease (STD) surveillance	<p>These data are used in reports of notifiable STDs such as syphilis, gonorrhea, chancroid, and chlamydia. Use STD surveillance data to obtain the number of cases and incidence of specific STDs. Demographic and clinical data are available from STD surveillance data. They may serve as a surrogate marker for unsafe sexual practices in a specific risk population. STDs are reportable in all 50 states and US territories. Despite widespread availability, reporting of STDs from private-sector providers may be less complete. Although STDs are the result of unsafe sexual behavior, STDs are not necessarily good predictors of HIV infection.</p>	<p>Available in all 50 states and US territories. Contact the STD program manager in your service area for information.</p>
Socioeconomic data	<p>Socioeconomic data are used to describe characteristics (e.g., income, education, poverty level) of persons in the service area.</p>	<p>Available for state and metropolitan areas from the Bureau of the Census and the Bureau of Labor Statistics. Additionally, states maintain census and labor statistics centers. Obtain these data from <a href="http://www.census.gov">http://www.census.gov</a>, <a href="http://www.bls.gov">http://www.bls.gov</a>, and state census centers.</p>
Special studies and surveys at the local level	<p>Surveys and other data collected from community-based organizations, AIDS service organizations, universities, and special studies. Includes recurring surveys in at-risk populations.</p>	<p>Local researchers and universities</p>

Type of Data	Description	Where to Obtain
Substance abuse data	Substance abuse data are obtained from population-based surveys, medical examiner records, correctional facilities, law enforcement agencies, and drug treatment centers. These sources describe the patterns, prevalence, and consequences of drug use in the general population and specific populations.	National Institutes of Health ( <a href="http://www.drugabuse.gov/NIDAHome.html">http://www.drugabuse.gov/NIDAHome.html</a> ); Substance Abuse and Mental Health Services Administration ( <a href="http://www.samhsa.gov">http://www.samhsa.gov</a> ) for information from drug-use surveys and data on treatment and drug abuse; National Institute of Justice ( <a href="http://www.adam-nij.net">http://www.adam-nij.net</a> ) for drug abuse among persons who have been arrested
Tuberculosis surveillance	<p>All 50 states, the District of Columbia, New York City, Puerto Rico, and other US jurisdictions in the Pacific and Caribbean report tuberculosis (TB) cases to CDC on a standard case report form. In 1993, in conjunction with state and local health departments, CDC implemented an expanded surveillance system to collect additional data to</p> <ul style="list-style-type: none"> <li>• better monitor and target groups at risk for TB</li> <li>• estimate and follow the extent of drug-resistant TB</li> <li>• evaluate outcomes of TB cases</li> </ul> <p>Although information on HIV status among reported TB cases is available, it may not be complete because of</p> <ul style="list-style-type: none"> <li>• confidentiality concerns that limit the exchange of data between TB and HIV/AIDS programs</li> <li>• local or state laws and regulations that prohibit the HIV/AIDS program and the TB program from sharing information about patients</li> <li>• reluctance of health care providers to report HIV test results to the TB surveillance program staff</li> <li>• a lack of counseling and HIV testing for some TB patients</li> </ul>	Available in all 50 states and US territories. Contact the TB program manager in your service area for information.
Vital records	<p>Vital records contain information, as stipulated by state statutes, on all births and deaths in the 50 US states, the District of Columbia, and US territories. For example, death records include</p> <ul style="list-style-type: none"> <li>• the cause of death according to the rules of the National Center for Health Statistics and the International Classification of Diseases (ICD-9 or ICD-10)</li> <li>• date of death</li> <li>• demographics of the deceased</li> </ul>	All states maintain registries of deaths. Contact the State Vital Records Registrar.